



King's Research Portal

DOI:

[10.1080/13548506.2011.555945](https://doi.org/10.1080/13548506.2011.555945)

Document Version

Early version, also known as pre-print

[Link to publication record in King's Research Portal](#)

Citation for published version (APA):

Stevelink, S., van Brakel, W. H., & Augustine, V. (2011). Stigma and social participation in Southern India: differences and commonalities among persons affected by leprosy and persons living with HIV/AIDS. *Psychology, Health & Medicine*, 16(6), 695-707. <https://doi.org/10.1080/13548506.2011.555945>

Citing this paper

Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights

Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the Research Portal

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

**Stigma and Social Participation in Southern India: Differences and Commonalities among
Persons Affected by Leprosy and Persons Living with HIV/AIDS**

S.A.M. Stevelink, VU University Amsterdam, The Netherlands

W. H. van Brakel, Athena Institute, VU University Amsterdam and Royal Tropical Institute, Leprosy
Unit, Amsterdam, The Netherlands

V. Augustine, Schieffelin Institute of Health-Research and leprosy Centre, Karigiri, India

Abstract

Stigma is a common phenomenon worldwide and infectious diseases like HIV/AIDS and leprosy are often associated with high levels of stigma. Several studies have been conducted concerning the effects of stigma and the impact on social participation, but comparative studies are rare. The objective of this study was to identify differences and similarities between HIV/AIDS and leprosy-related stigma. From April till July 2009, 190 questionnaire-based interviews were conducted, to assess the levels of internalized stigma (Internalized Stigma of Mental Illness scale), perceived stigma (Explanatory Model Interview Catalogue stigma Scale) and social participation (Participation Scale) in a cross-sectional sample of people affected by leprosy (PL) and people living with HIV/AIDS (PLHA). Respondents were selected from several hospitals, charity projects and during home visits in Vellore district, Tamil Nadu. Our results showed that both PLHA (n=95) and leprosy-affected respondents (n=95) faced a substantial burden of internalized and perceived stigma, with the former reporting a significantly higher level of stigma. As a result, PLHA faced more frequent and also more severe participation restrictions than PL. Especially restrictions in work-related areas were reported by the majority of the respondents. In conclusion, PLHA faced a significantly higher level of stigma and participation restriction than PL. However, the latter also reported a substantial burden of stigma and participation restrictions. The study suggests that it may be possible to develop joint interventions based on the commonalities found. More research is needed to define these more precisely and to test the effectiveness of such joint interventions in reducing stigma and improving social participation.

Keywords: *HIV/AIDS, India, Leprosy, Measurement, Social participation, Stigma*

Introduction

Health-related stigma is a common phenomenon worldwide. Many people suffering from a chronic health condition are stigmatized due to this condition (Heijnders & Van Der Meij, 2006). Not only does the condition have an impact on the person affected, but these persons are often more vulnerable to other health problems also. Stigmatized persons are frequently identified with other conditions and situations that are stigmatized, for example poverty, sexual preferences and ethnicity (Parker & Aggleton, 2003). Often, the stigma related to these health conditions is often even more destructive to the affected person than the health conditions themselves (Mak et al., 2006). Stigma impacts on marriage, employment, educational opportunities, friendship, self-esteem and may result in a high burden of emotional stress and anxiety and a more severe depressive status (Tsutsumi et al. 2004;Tsutsumi et al. 2007;Van Brakel 2006). Stigma also has a negative impact on public health interventions (Weiss, 2008). People may fear going to the health services, resulting in delay in diagnosis and poor treatment adherence, which can cause drug resistance and increase risk of disability (Heijnders & Van Der Meij 2006;Van Brakel 2006;Weiss and Ramakrishna 2006).

Infectious diseases, such as HIV/AIDS and leprosy are frequently associated with high levels of stigmatization (Weiss et al., 2006). This is probably due to the fear of contagion, but the association with physical and psychological morbidity may also be a contributing factor (Link and Phelan 2001;Malcolm et al. 1998). Sometimes, access to health care services is denied, people are avoided by their neighbours and colleagues, and relationships with family and friends are disrupted. Additionally, negative effects of stigma are reported regarding test-seeking behaviour, treatment uptake and treatment adherence (Bekri et al. 1998;Chalise 2005;Crandall and Coleman 1992;Heijnders & Van Der Meij 2006;Herek 1999;Ma et al. 2007;Malcolm, Aggleton, Bronfman, Galvão, Mane, & Verrall 1998;Weiser et al. 2003). The causes for stigmatization of leprosy-affected persons are widely discussed in the literature. Important causes include the assumption of the community that the affected person is to blame, e.g. because the affected person has committed ‘sin’ and needs to pay for this

mistake. The fear of contagion and the association with disability and deformity are other causes for stigmatization (de Stigter et al. 2000;Myint et al. 1992;Rafferty 2005;Zodpey et al. 2000).

When comparing the results of research regarding stigmatization across different health conditions, many similarities in the effects of stigma are evident. A review by van Brakel (2006) concluded that the consequences of health-related stigma are remarkably similar across the different health conditions, cultures and public health programs. It may therefore be possible to set up joint interventions for different health conditions, such as HIV/AIDS and leprosy. However, more evidence is needed to support this assumption. Until now, comparative studies are rare. Some previous work was done comparing leprosy, epilepsy and tuberculosis (TB) and HIV/AIDS, SARS and TB (Croft and Croft 1999;Mak, Mo, Cheung, Woo, Cheung, & Lee 2006;Tekle-Haimanot et al. 1992) . A direct comparison between stigma experienced by persons living with HIV (PLHA) and people affected by leprosy (PL) has never been made. Therefore, the main purpose of this study was to determine the differences and similarities in the effects of stigma among PLHA and PL. This comparative study aimed to contribute to the body of knowledge on leprosy and HIV-related stigma and to provide possible leads for interventions.

Methods

This cross-sectional study was conducted between April 2009 and July 2009 in Tamil Nadu, Southern India. A convenience sample was recruited from 3 hospitals, several charity projects and during home visits. Before starting with the interviews, the interpreters explained the purpose of the study to the respondents, after which written informed consent was obtained. Subjects were considered eligible to participate if they were at least 18 years old; had a diagnosis of leprosy or HIV/AIDS confirmed by the participant; were diagnosed with this condition at least 3 months ago; had no recent diagnosis of another health condition; and were capable of communicating verbally in Tamil.

Four native language-speaking interpreters were trained to conduct the questionnaire-based scale interviews. The majority of the instruments used were validated in Tamil in the recent SARI Pilot

Project (Rensen et al., 2010). Additionally, a small pilot study was conducted to validate the scales for the HIV/AIDS population. Since no major adjustments were necessary, these respondents were included in the main study sample. The study protocol was approved by the Research Ethics Committee of the Schieffelin Institute of Health-Research and Leprosy Centre. Transport cost were reimbursed for respondents who lived a large distance from the study site.

Instruments

Three questionnaire-based scales were used in a single interview session:

Explanatory Model Interview Catalogue stigma Scale (EMIC): an adapted version of the EMIC was used to measure the level of perceived stigma (Weiss, 1997). The scale consisted of 17 items with four answer possibilities namely 'yes' (3 points), 'possibly' (2), 'uncertain' (1) and 'no' (0). The higher the score, the higher the level of perceived stigma. Several features of stigma and areas of life commonly affected by stigma were covered in this scale such as concealment, avoidance, pity and shame. The scale has been shown to have good reliability (Rensen et al., 2010).

Internalized Stigma of Mental Illness scale (ISMI): A 28-item version of the ISMI was used in our study (Ritsher et al., 2003). Alienation, stereotype endorsement, perceived discrimination, social withdrawal and stigma resistance were examined with a 4-point agreement scale, a higher score indicating a higher level of internalized stigma. The ISMI has been shown to have good internal consistency and reliability (Rensen et al., 2010).

Participation Scale (P-Scale): The 18 item P-Scale (v. 5.2) was used in our study to measure the level of (social) participation (Van Brakel et al. 2006). Most domains of participation are included in this scale, such as employment, mobility, interpersonal interactions and community, social and civic life. When a respondent reports a restriction in participation, the person is asked to indicate how big that problem is to him or her, namely no problem (1), small problem (2), medium problem (3) or large problem (5). The higher the score, the higher the level of participation restrictions. The P-scale has been shown to have very good internal consistency and reliability (van Brakel et al., 2006; Stevelink et al., 2010, in preparation)

Statistics

Data were entered into a database written using Epi-Info (v. 3.5.1) and converted for analysis to SPSS (v.16.0). Cronbach's alphas were determined for each scale. . The Chi-square test was used to check for significant differences in the demographic variables between PLHA and PL. To compare the stigma scores of PLHA and PL the sum scores of the EMIC and P-scale and the mean item score of the ISMI were used. Before analysis the reverse coded items from the ISMI and EMIC were recoded to get appropriate results. The influence of several determinants on the scores was analyzed using linear regression analysis. A p-value of ≤ 0.05 was considered as statistically significant.

Results

As summarized in Table 1, a total of 190 respondents were included in the study, 99 males and 91 females. The mean age of the 95 PLHA was 36.9 (SD 7.0; range 20-52) and that of the 95 PL was 34.5 (SD 9.2; range 19-53). Most were living in rural areas (77%); however, the percentage of the PLHA living in an urban setting was significantly higher than the percentage of PL (32% vs. 15%, $p=0.006$). Significant differences were found in marital status between the respondent groups, $p=0.024$. PLHA were more often widowed (40%) than the PL (9%), and were less often 'never married' (5%) in comparison to the latter (21%). In total, 25% of the total population was illiterate and more than 90% of the respondents earned less than 3000 rupees a month. There was no significant difference between the reported health status of the respondents; 68% of the respondents reported their health as good or very good.

The time since diagnosis among the PL ranged from 3 months to 40 years, with a mean of 6.2 years. Fifty percent of the respondents were on Multi Drug Therapy (MDT). Only 65% had told their spouse that they were affected by leprosy and, reportedly, only 31% of the children knew that their mum or dad was affected. Eleven respondents (12%) had told no one that they had this disease.

The time since PLHA were diagnosed ranged from half a year to 20 years, with a mean of 4.7 years. Seventy-two percent received Anti-Retroviral Therapy (ART). In only 56% of the cases, the spouse knew that the person was HIV affected and in only 28%, the diagnosis had been disclosed to the children. 7 respondents had not disclosed their status to anyone (7%).

Table 1 Socio-demographic characteristics of the sample

Variables	HIV/AIDS (n = 95)	Leprosy (n = 95)	Total (N = 190)	Difference between groups
Sex:				ns*
Male	48 (50.5%)	51 (53.7%)	99 (52.1%)	
Female	47 (49.5%)	44 (46.3%)	91 (47.9%)	
				0.017
Age:				
19-25	4 (4.2%)	16 (16.8%)	20 (10.5%)	
26-35	41 (43.2%)	37 (38.9%)	78 (41.1%)	
36-45	39 (41.1%)	27 (28.5%)	66 (34.7%)	
46-53	11 (11.6%)	15 (15.8%)	26 (13.6%)	
				ns
Religion:				
Hindu	77 (81.1%)	81 (85.3%)	158 (83.2%)	
Other	18 (18.9%)	14 (14.7%)	32 (16.8%)	
				0.006
Residency:				
Urban	30 (31.6%)	14 (14.7%)	44 (23.2%)	
Rural	65 (68.5%)	81 (85.3%)	146 (76.8%)	
				0.024
Marital Status:				
Never married/ widowed/separated	43 (45.3%)	28 (29.5%)	71 (37.4%)	
Married/remarried/cohabit	52 (54.7%)	67 (70.5%)	119(62.6%)	
				<0.001
Children:				
Parity	84 (88.4%)	63 (66.3%)	147 (77.4%)	
Non-parity	11 (11.6%)	32 (33.7%)	43 (22.6%)	
				0.012
Education:				
Literate	79 (83.2%)	64 (67.4%)	143 (75.3%)	
Illiterate	16 (16.8%)	31 (32.6%)	47 (24.7%)	
				0.025
Occupation Respondent:				
Unemployed	16 (16.8%)	21 (22.1%)	37 (19.5%)	
Housewife	6 (6.3%)	12 (12.6%)	18 (9.5%)	
Trade/business	5 (5.3%)	13 (13.7%)	18 (19.5%)	
Labour	68 (71.6%)	49 (51.6%)	117 (61.6%)	
				ns
Income Respondent: (rupees per month)				
No income	22 (23.2%)	35 (36.8%)	57 (30.0%)	
Less than 1000	46 (48.4%)	30 (31.6%)	76 (40.0%)	
1001-3000	21 (22.1%)	24 (25.3%)	45 (23.7%)	
>3001	6 (6.3%)	6 (6.3%)	12 (6.3%)	
				ns
General health:				
Very bad/bad	10 (10.5%)	9 (9.5%)	19 (10.0%)	
Moderate	21 (22.1%)	19 (20.0%)	40 (21.1%)	
Good	59 (62.1%)	57 (60.0%)	116 (61.1%)	
Very good	5 (5.3%)	10 (10.5%)	15 (7.9%)	

*Chi-squared test

EMIC; perceived stigma

The mean sum score of the EMIC was 21.8 for the PLHA and 15.1 for the PL. The multivariate analysis, controlling for the effects of age, religion and health status, showed that leprosy-affected respondents had a significantly lower score on the EMIC with 5.9 points ($p<0.001$) (Table 2). Age, religion and health status also had a significant independent effect on the level of perceived stigma. The reliability of the EMIC was adequate. The leprosy version of the scale had a Cronbach's alpha of $\alpha=0.83$ and the HIV/AIDS version an alpha of $\alpha=0.76$.

Table 2
Linear regression analysis EMIC; perceived stigma; N=190

	Univariate			Multivariate*		
	Coef	(SE)	P	Coef	(SE)	P
Type of respondent	-6.76	(1.49)	<0.001	-5.86	(1.37)	<0.001
Age	2.62	(0.89)	0.004	1.67	(0.81)	0.039
Religion	4.37	(2.07)	0.036	4.07	(1.82)	0.027
Children	5.30	(1.83)	0.004	ns		
Income	-1.76	(0.88)	0.045	ns		
Health status	-5.24	(0.96)	<0.001	-4.74	(0.90)	<0.001

Only significant variables are presented. ns = not significant, hence not included in the multivariate model. Coef = regression coefficient; SE = standard error.

*R² 0.26

Profile of perceived stigma

The differences between PL and PLHA were examined using a profile perceived stigma (Fig. 1). The answer options 'yes' and 'possibly' were considered to indicate perceived stigma. Significantly more PLHA said that they try to 'keep people from knowing about their condition' compared to PL ($p=0.044$). Other significant differences were found in the items 'made to feel ashamed' ($p<0.001$) and 'less respect from others' ($p<0.001$) with HIV/AIDS respondents answering 'yes' or 'possibly' significantly more often. In general, PLHA scored 10-20% higher on items concerning avoidance, refusal to visit the home of the respondent, problems in marriage and support from parental and in law family. More than 50% of the PLHA thought that others were thinking less of their family and that their condition causes problems for their children, compared to around 40% of the PL. Problems in

marriage and in finding a marriage partner were reported more frequently by HIV/AIDS-affected respondents.

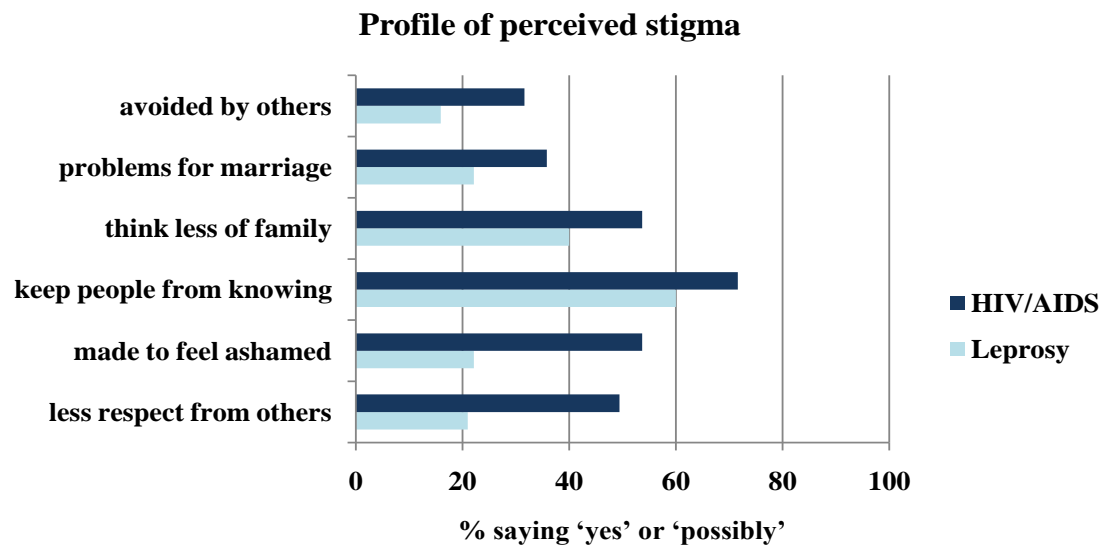


Fig. 1. EMIC; profile of perceived stigma

ISMI; internalized stigma

The mean item score of the ISMI was 2.3 for PLHA and 2.2 for PL. After adjustment for age, education and health status this difference between the respondents was still borderline significant ($p=0.056$) with a coefficient of -0.14 points (Table 3). The scale had an excellent internal consistency of respectively $\alpha=0.91$ and $\alpha=0.87$ for the leprosy and HIV/AIDS-affected respondents.

Table 3
Linear regression analysis ISMI; internalized stigma; N=190

	Univariate			Multivariate*		
	Coef	(SE)	P	Coef	(SE)	P
Type of respondent	-0.15	(0.08)	0.061	-0.14	(0.07)	0.056
Age	0.16	(0.05)	<0.001	0.09	(0.04)	0.032
Education	0.24	(0.09)	0.010	0.20	(0.09)	0.020
Income	-0.11	(0.05)	<0.001	ns		
Health status	-0.33	(0.05)	<0.001	-0.30	(0.05)	<0.001

Only significant variables are presented. ns = not significant, hence not included in the multivariate model. Coef = regression coefficient; SE = standard error.

* $R^2=0.27$

Profile of internalized stigma

The majority of the respondents reported that they were disappointed in themselves for contracting the disease and felt embarrassed (60-70%). Significant differences were present on the mean item scores of ‘affected people should not marry’ ($p<0.001$), ‘ignore or take me less serious’ ($p<0.001$), and ‘stay away from social situations, protect family’ ($p<0.001$) (Fig. 2). PLHA scored higher on these items as well as on items regarding discrimination, ‘the condition has spoiled my life’, ‘nobody get close’ and patronizing behaviours from others. The percentage that ‘agreed’ or ‘strongly agreed’ with these items ranged from 40-60% for the PLHA and 20-50% for the leprosy-affected respondents. The majority of the respondents reported that they were ‘able to live life they wanted’ and ‘live a good life despite the condition’ (60-70%).

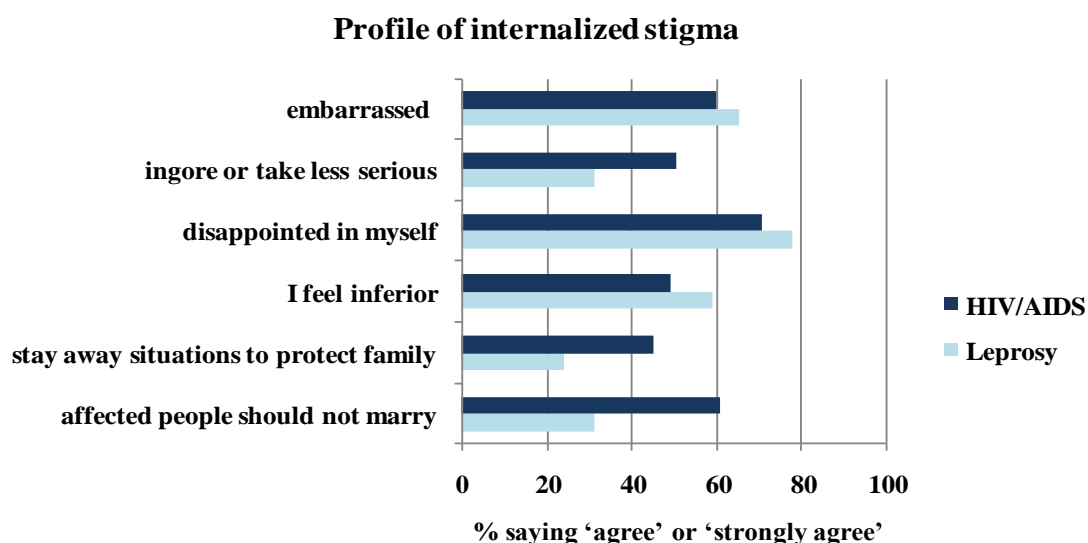


Fig. 2. ISMI; profile of internalized stigma

Participation Scale; social participation

The mean P-score of the PLHA and leprosy-affected respondents was 16.0 and 10.1 points, respectively (Table 4). This difference was still present after adjusting for the effects of age, income and health status, showing that PL scored significantly lower (5.2 points; $p=0.005$). Only type of respondent, income and health status had a significant independent effect on the perceived level of participation. The scale had an excellent internal consistency for both PL and PLHA ($\alpha=0.87$ and 0.86 , respectively).

Table 4
Linear regression analysis P-Scale; social participation; N=190

	Univariate			Multivariate*		
	Coef	(SE)	P	Coef	(SE)	P
Type of respondent	-5.91	(2.23)	0.009	-5.16	(1.83)	0.005
Age	2.43	(1.31)	0.066	ns		
Income	-3.77	(1.25)	0.003	-2.64	(1.04)	0.012
Health status	-11.43	(1.23)	<0.001	-10.79	(1.21)	<0.001

Only significant variables are presented. ns = not significant, hence not included in the multivariate model. Coef = regression coefficient; SE = standard error.
 $R^2: 0.36$

Profile of social participation

A profile of participation restrictions was made classifying the answer options 'yes' and 'no problem' as 'no restriction' and 'small problem', 'medium problem' and 'large problem' as an indication for 'participation restrictions'. The results indicate that many respondents reported restrictions in relation to work, with a significant difference for the item 'contribute economically' ($p=0.047$) (Fig. 3). The respondents had fewer problems in the social part of their life, such as going to festivals, visit public places and other people and move around the house. One item showed a striking difference namely 'same respect'. Around 10% of the PL reported that they did not receive the 'same respect' as their peers, while this was around 30% among PLHA ($p<0.001$). In other areas, such as doing household work, learning new things and meeting new people, only few respondents reported restrictions.

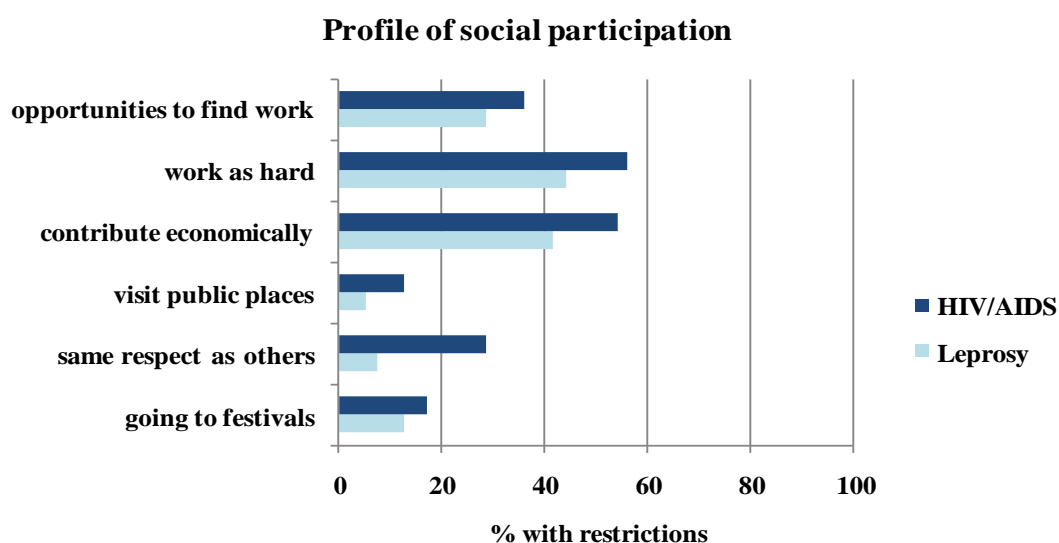


Fig. 3. P-Scale; profile of social participation

Discussion

The objective of this study was to determine whether and how stigma differs across PLHA and PL and in which ways it is similar. The results suggested that, in general, most respondents in both groups reported a substantial burden of internalized and perceived stigma, and restrictions in social participation. However, PLHA faced a higher burden of stigma and had more severe levels of participation restrictions than PL.

A literature search was done to compare our findings with previous studies. Some comparative stigma studies were found, merely concerning public attitudes. However, no other publications were identified that compared stigma among PLHA and persons affected by leprosy. A study in Hong Kong compared stigma related to HIV/AIDS, SARS and TB (Mak et al., 2006). They showed that more stigmatizing perceptions were present about HIV (36.8%) than about TB (3.7%) and SARS (4.9%). The authors concluded that the general public stigmatized HIV/AIDS more than TB and SARS, because of the association with immoral behaviour, as intravenous drugs use and promiscuity, and higher levels of self-controllability and responsibility. These findings agree with ours, in that PLHA faced a higher burden of stigma than the PL. In our study, 20-30% of the PL reported experiences of discrimination, being ignored or treated like a child and of people keeping distance from them, compared to 40-50% of the HIV/AIDS respondents. Previous work done in South Africa found that more than 30% of the PLHA reported feelings of guilt, shame and dirtiness because of their positive status (Simbayi et al., 2007). In our study sample, two out of three respondents reported feelings like this. Leprosy is seen as a curable disease, but one that is highly contagious, whereas HIV/AIDS infection is seen as incurable and more under people's own control. Therefore PLHA are held more responsible for contracting the disease (Barkataki et al. 2006; de Stigter, de Geus, & Heynders 2000; Mak, Mo, Cheung, Woo, Cheung, & Lee 2006; Nyblade et al. 2003; Rafferty 2005).

People's opinion was asked about the statement 'affected people should not marry'. Of the PLHA and PL, 61% and 32%, respectively (strongly) agreed with this statement. Also 36% of the PLHA and 20% of the PL reported marital problems due to the disease. An explanation for the higher percentage

among PLHA may be found in the awareness of contagiousness and, different from PL, the route of (sexual) transmission of HIV/AIDS. Additionally, the association with death may increase this perception. One might conclude that both conditions frequently cause marital problems. Counselling of the affected persons and their spouses should address this problem.

In Bangladesh, a small study compared the knowledge, attitudes and practice concerning leprosy and TB in two intervention areas (Croft & Croft, 1999). The intervention consisted of the provision of health education in the selected area. Almost no differences were reported in the attitudes towards leprosy and TB, and for both conditions high levels of stigma were still present, especially in the area where no health education program was provided. In this area, 74% and 76% of the respondents would not allow a TB or leprosy patient to eat with their family and, respectively, 88% and 94% would not allow their son to marry with someone cured of TB or leprosy. Less negative attitudes were found in the community households that were exposed to a higher level of health education, with prejudicial answer percentages ranging from 24% to 30% on the questions. These findings, and ours, confirm the universal nature of health-related stigma and its consequences, along with the potential of different kinds of interventions.

Around 50% of the PLHA compared to 40% of the PL stated that the community thought less of their family due to their illness. Of the PLHA, 45% said that they stayed away from social events in order to protect their family or friends from embarrassment, compared to 24% of the respondents affected by leprosy. By staying away from social events, PLHA might try to protect their family from being stigmatised also. Previous work showed that families of PLHA often faced such 'courtesy stigma'. Especially children and other family members are stigmatized because the status of the person affected. Gossiping and social exclusion are examples of these practices (Nyblade et al., 2003). Courtesy stigma experiences were reported as well in former work concerning leprosy (de Stigter, de Geus, & Heynders 2000; Kopparty et al. 1995; Sleaf 2001). Our results indicate that many respondents have a negative self-image and a negative perception of the way they are treated by others.

High levels of non-disclosure were reported by the respondents. Of the PLHA, 35% had not disclosed their status to their spouse, compared to 44% of the PL. This non-disclosure is likely to increase the risk of transmission, resulting in an increased burden of preventable morbidity and mortality. In addition, hiding one's status from close family members, friends or colleagues can cause severe 'hidden distress' (Scambler & Hopkins, 1990). This can cause considerable psychological stress (Pachankis, 2007).

The high levels of stigma reported by our respondents, contributed to substantial levels of participation restrictions. Among the participation problems reported, difficulties in work-related areas, such as the opportunity to find work and the ability to work as hard as their peers, were the most frequent.

Previous work done in South Africa showed that leprosy-affected respondents were afraid of losing their job due to their disease and that employers were afraid or expected a decline in productivity (Scott, 2000). In the areas of social life, such as visiting other people, going to social activities and moving in and around the house, only a minority (~10% leprosy and ~20% PLHA) reported restrictions.

Study limitations

First, for the enrolment of leprosy-affected respondents in our study, we were dependent on the referral of the doctors at the centre. Some respondents were really upset due to their condition and were therefore already excluded by the doctors. As a consequence, some subjects with a really high burden of stigma and restrictions may have been excluded from the study. This may have led to an underestimation of the overall severity of stigma in the leprosy-affected group. Second, about 75% of the leprosy-affected respondents were selected during their attendance at the hospital. This may have resulted in somewhat different findings from when respondents had been selected in a community setting. People who attend the hospital have, on average, more severe disease than those who don't and possibly also more severe stigma. Third, only 15% of the PLHA were selected from a hospital-based setting; the majority were included with help of charity organizations and interviewed in the community. These respondents were often involved in a special program for PLHA where emotional

support or economic assistance was given or facilities were provided for their children. This may have resulted in an underestimation of stigma and participation restrictions. Finally, the possibility of ‘social desirability’ is present in the answers given by the respondents. In that case, our findings might be an underestimation of the burden of stigma and participation restrictions. The reverse is also possible, particularly if people had hopes to get (additional) help from the institute.

Despite these limitations, we are confident that the findings of the present study are a fair representation of the level of HIV and leprosy-related stigma and its effects.

Interventions and further research

Our findings indicate that it may be possible to develop joint interventions based on the similarities in perceived and experienced stigma and participation restrictions among HIV/AIDS and leprosy-affected people. Especially in work-related areas, common interventions would be appropriate, as well as in the area of feelings of shame, blame, inferiority and lack of respect. Social support programs and counselling would be important combined with skill development training, education and contact with affected persons (Brown et al. 2003; Heijnders & Van Der Meij 2006). Furthermore, there would be a good potential for integration of care regarding HIV/AIDS and leprosy (Arole et al., 2002). People with either condition could be helped by the same service providers. People with other stigmatised conditions could benefit from such services also.

However, the construct and experience of stigma is very dynamic and dependent on the context of the person, so sensitivity is needed to the personal circumstances of the one affected. Additionally, the experience of similar problems due to stigma, does not guarantee equal effectiveness of similar intervention strategies for different types of respondents. Research is needed to compare levels and patterns of stigma related to other health conditions, and to test the effectiveness of joint interventions.

Acknowledgements

This research was partly supported by a grant received from the Netherlands Leprosy Relief and the Dittmer Fund. We would like to express our gratitude to all of the patients who participated in the

study, the staff members of the Schieffelin Institute of Health- Research and Leprosy Centre and the research assistants. Without the facilities and the support from the Schieffelin Institute of Health- Research and Leprosy Centre this study would not have been possible.

Reference List

- Arole, S., Premkumar, R., Arole, R., Maury, M., & Saunderson, P. (2002). Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. *Lepr.Rev.*, 73, 186-196.
- Croft, R. P. & Croft, R. A. (1999). Knowledge, attitude and practice regarding leprosy and tuberculosis in Bangladesh. *Lepr.Rev.*, 70, 34-42.
- Heijnders, M. & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychol.Health Med.*, 11, 353-363.
- Mak, W. W., Mo, P. K., Cheung, R. Y., Woo, J., Cheung, F. M., & Lee, D. (2006). Comparative stigma of HIV/AIDS, SARS, and tuberculosis in Hong Kong. *Soc.Sci.Med.*, 63, 1912-1922.
- Nyblade, L., Pande, R., Mathur, S., MacQuarri, K., Kidd, R., Banteyerga, H. et al. (2003). *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia* Washington DC: International Centre for Research on Women.
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: a cognitive-affective-behavioral model. *Psychol.Bull.*, 133, 328-345.
- Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc.Sci.Med.*, 57, 13-24.
- Rensen, C., Bandyopadhyay, S., Gopal, P. K., & Van Brakel, W. H. (2010). Measuring leprosy-related stigma - a pilot study to validate a toolkit of instruments. *Disabil.Rehabil.*.
- Ritsher, J. B., Otilingam, P. G., & Grajales, M. (2003). Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research*, 121, 31-49.
- Scambler, G. & Hopkins, A. (1990). Generating a model of epileptic stigma: the role of qualitative analysis. *Soc.Sci.Med.*, 30, 1187-1194.
- Scott, J. (2000). The psychosocial needs of leprosy patients. *Leprosy Review*, 71, 486-491.
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Soc.Sci.Med.*, 64, 1823-1831.

- Weiss, M. (1997). Explanatory Model Interview Catalogue (EMIC):Framework for Comparative Study of Illness. *Transcultural Psychiatry*, 34, 235-263.
- Weiss, M. G. (2008). Stigma and the social burden of neglected tropical diseases. *PLoS Negl.Trop.Dis.*, 2, e237.
- Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: rethinking concepts and interventions. *Psychol.Health Med.*, 11, 277-287.